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Title: Understanding alcohol-related liver disease patients' illness beliefs and views about their medicine.

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INTRODUCTION

Alcohol is believed to be a factor in 80% of cases of liver cirrhosis in the UK and carries a poorer prognosis than other causes (McCarron & Welter 2012, Thompson et al 2008). Alcohol-related liver disease (ALD) also makes a major contribution to a rise in hospital admissions and mortality rate (Neame & Hammond 2005). As a chronic condition, patients with ALD are often required to take diuretics and laxatives for the rest of their lives.

These medications require constant monitoring and titrating of effect, carrying substantial side effects while often their intended effect may not be readily apparent. 30 – 50% of all patients do not take their treatment as prescribed, leading to a significantly increased risk of morbidity and mortality (Horne et al 1999), and there is every reason to suspect that people with ALD are no exception.

Horne et al (1999) argue that existing trials exploring medication non-adherence lack underpinning theory. Usually they are only concerned with addressing unintentional factors, ignoring the motivation of the patient, and thus only addressing half of the problem.

The nature of non-adherence is complex Gatti et al (2009). Horne describes the causes of non-adherence as being either intentional or unintentional, both of which need to be addressed to tackle the problem effectively. Unintentional

causes are largely beyond the patient's control, but intentional non-adherence is a deliberate choice by the patient not to act, implying an issue of motivation. Gatti et al (2009) suggest that attitudes and beliefs about illness and medication strongly influence the likelihood of a patient adhering to their treatment. Research in this area is sparse. No research has been carried out on medication adherence and specifically patients with ALD. This paper is the first to explore their views about medicine and the relationship with their illness beliefs, socio-demographic factors and clinical data. The study findings can be used to develop tools to enhance medication adherence in patients with ALD.

Psychological models have been developed to examine issues of individual motivation and health related behaviour, notably the Health Belief Model (HBM) (Becker 1974), the Theory of Planned Behaviour (TPB) (Ajzen 1985), Self-efficacy (Bandura 1997) and the Self-regulatory Model of Illness (SRM) (Leventhal et al 1984). These models commonly identify patients' illness beliefs as significant influences on health behavior changes. In the SRM, patients' previous experience of illness is organized in a complex memory structure that is used to cluster and organize illness knowledge. Numerous research findings identifying illness representation components within the SRM framework (identity, cause, timeline, consequences and control/cure) as predictors of health outcomes. This has led to the creation of the Illness Perception Questionnarie (IPQ) (Weinman et al 1996) and later a short-form (BIPQ) (Broardbent 2006), used in this study.

Research question

Is there an association between perceptions of illness symptoms (Illness belief component 'identity') and views of medication for patients with ALD?

Study objectives

1. To understand the views about medicines held by patients with ALD.
2. To determine to what extent illness perception, self-reported alcohol intake and severity of disease influence patients' views about their medicine.

METHOD

Design

An observational cross sectional survey was carried out on patients with ALD who attended the Liver Outpatient Clinic at a London Hospital over a period of 12 months (October 2012 to November 2013). They were invited to complete a set of validated instruments measuring illness beliefs and views about their medicine.

Participants

Inclusion Criteria

- Patients with a confirmed primary diagnosis of ALD attending the outpatient clinic were eligible for the study.

Exclusion criteria

-Patients below 18 years of age

-Patients unable to understand and read English unaided which would affect their ability to participate in the study

-Patients with severe cognitive impairment that prevented them from answering the questionnaires of the study even with assistance available.

Data collection

Patients were screened by an ALD Nurse Specialist and those who met criteria were invited to participate in the study. After gaining informed consent the participants completed a set of paper-based questionnaires. Additional data was acquired for demographics, body mass index (BMI) and Model of End-stage Liver Disease (MELD) score.

Measures

All instruments used have proven validity and reliability. Wherever possible the short forms of these measures were selected to encourage participation.

The following measures were used:

Outcome variables

Beliefs about Medicines Questionnaire (BMQ) (Horne & Weinman 1999)

To assess patients' views about their medicine, the BMQ consists of three components:

- Necessity Score (NS) - five statements regarding how necessary patients consider their medication to be, measured using a 5-point

Likert scale with a score from 5 to 25. The higher score, the deeper the appreciation of the need for medication.

- Concerns Score (CS) – five statements regarding how concerned patients are about the consequences of taking their medicine, measured as the NS. The higher score, the deeper the anxiety of the negative consequences of the medication.
- A Necessity/Concern Differential (NCDiff) was calculated by subtracting the CS from the NS, ranging from -20 to +20. The more positive the score, the greater the tendency toward medication adherence, whilst a negative score will indicate a greater tendency toward non-adherence.

Actual adherence to medication was not independently measured in this study as the primary concern was to assess motivations behind non-adherent acts.

Explanatory variables

Brief Illness Perception Questionnaire (BIPQ) (Broardbent 2006)

Provides a quantitative assessment of the illness perception components described in Leventhal's SRM [15]. The BIPQ consists of eight components measured on a zero to ten Likert scale:

- Consequences - How much does your illness affect your life?
- Timeline - How long do you think your illness will continue?
- Personal control - How much control do you feel you have over your illness?
- Treatment control - How much control do you think your treatment can help your illness?
- Identity - How much do you experience symptoms from you illness?

- Concerns - How concerned are you about your illness?
- Illness comprehension - How well do you feel you understand your illness?
- Emotions- How much does your illness affect your emotionally? (e.g. does it make you angry, scared, upset or depressed?)

The Alcohol Use Disorders Identification Test – Consumption (AUDIT-C)

Three alcohol consumption questions used for the assessment of heavy drinking behaviors. A score of five or above is considered to be hazardous drinking Bradley et al 2007).

The Model for End-Stage Liver Disease (MELD) score

MELD score determines severity of chronic liver disease is used to predict mortality in patients awaiting transplant with a MELD of 20 generally being considered for transplantation (O'Grady et al).

Demographic data and illness characteristics

Gender, age, marital status, living arrangements, employment status, level of education, and ethnicity.

Additional lifestyle information was body mass index (BMI), whether the patient is currently a smoker, and whether the patient has other chronic illnesses.

This data was collected to allow for variable analysis adjustments. The study was not powered to determine whether they were independent factors in predicting adherence to medication.

Statistical Hypotheses

1. The eight BIPQ components, MELD and AUDIT-C are not individually associated with NC, CS and NCDiff
2. There is not a combined, or simultaneous, effect of the eight BIPQ components, MELD and AUDIT-C on NC, CS and NCDiff after adjusting for demographic and illness characteristic variables.

Ethical considerations

Ethical approval was obtained from the National Research Ethic Service Committee and the study was registered with the Research and Development Department at the hospital concerned.

Data Analysis

The strength of association between Necessity Score (NS), Concerns Score (CS) and Necessity/Concern Differential (NCDiff) and the eight Brief Illness Perception Questionnaire (BIPQ) components, Model for End-Stage Liver Disease (MELD) and Alcohol Use Disorders Identification Test – Consumption (AUDIT-C) were measured using Pearson's correlation coefficient.

Three multiple regression models with outcome variables: NS, CS & NCDiff were regressed on the eight BIPQ components, MELD & AUDIT-C, adjusting for demographics and illness characteristics. 5% level of significance has been used throughout.

RESULTS

Demographic and illness characteristics

159 completed the questionnaire pack. Age ranged from 27 to 80 (mean 52.3) and two thirds were male. 19% were single and 53% lived with someone. Eighty one percent were white; 66% were born in the United Kingdom. One quarter held a university degree. 26% reported being in employment or on sick leave, 26% unemployed and 19% retired. Thirty-nine percent had comorbidities (e.g. diabetes, COPD). BMI was unknown for 34% of patients, 16% had a BMI ≥30 (obese) and BMI was <30 for 50%. Twenty nine percent reported being current smokers. Mean MELD and AUDIT-C Scores were 11.0 (range 6-28) and 3.46 (range 0-12) respectively (Table 1). Based on AUDIT-C 48% (n=71) of participants continued to drink alcohol of whom 56% (n=40) scored greater than 5.

Table 1: Sample Characteristics (demographics and illness characteristics – MELD /AUDIT C) table 1.

Demographics / Illness characteristics	Frequencies (%*) / Mean (SD) Range
Gender	

Male	107 (69)
Female	48 (31)
Unknown	4
Age*	
<44	32 (23)
45-54	50 (36)
>55	59 (41)
Unknown	18
Mean (SD) Range	52 (11) 27-80
Ethnic group	
White	128 (84)
Other ethnic groups/mixed	25 (16)
Unknown	6
Marital status	
Single	30 (20)
Partner but not living together	18 (13)
Married/living with partner	68 (46)
Divorced/ separated/ Widowed	31 (21)
Unknown	12
Living Arrangements	
Lives alone	42 (30)
Lives with others	99 (70)
Unknown	18
Employment	
Employed	30 (21)
On sick leave	11 (8)
Home maker	11 (8)
Retired	30 (21)
Not employed	42 (29)
Other	19(13)
Unknown	16

Education	
None	29 (21)
GCSE/ 'O' levels	29 (21)
'A' levels	15 (11)
University degree	39 (28)
Other qualification	16 (12)
Other	10 (7)
Unknown	21
BMI	
<18.5	6(6)
<30	79 (75)
>31	26 (25)
Unknown	54
Mean (SD) Range	26.7 (5.5) 16.5-40.2
Current smoker	
Yes	46 (32)
No	98 (68)
Unknown	15
MELD score	
Mean (SD) Range	11 (5) 6-28
Total AUDIT-C score	
>5	92 (66)
6<	48 (34)
Unknown	19
Mean (SD) Range	5 (5) 1-15

Views about their medicine

For the BMQ, NS was found to be higher than CS with means of 18.17(SD 4.88) and 12.16 (SD 4.42) respectively and NCDiff was positive with a mean of 6.00 (SD 5.24) (Table 2). Thirteen participants (9%) had negative NCDiff scores.

Table 2: Illness belief and views about their medicine – summary statistics				
Explanatory variables	n	Mean	SD	Range
Illness belief components:				
Consequences	159	5.77	3.03	0-10
Timeline	152	7.74	2.80	0-10
Personal control	158	3.99	2.90	0-10
Treatment control	151	2.21	2.33	0-10
Identity	158	5.32	3.04	0-10
Concerns	157	7.42	2.92	0-10
Illness Comprehension	157	2.15	2.41	0-10
Emotions	157	5.50	3.32	0-10
Outcome variables ***Views about their medicine:***	n	Mean	SD	Range
Necessity (NS)	142	18.17	4.88	5-25
Concern (CS)	142	12.16	4.42	5-25
Necessity-Concern difference (NCDiff)	142	6.00	5.24	-20 to +20

Beliefs about their illness

The illness belief component that produced the highest mean score was 'Timeline', followed by 'Concerns' and 'Consequences' (Table 2). 'Illness comprehension' (2.15) had the lowest mean score followed by 'Treatment control' (2.21) and 'Personal control' (3.99).

Association between Illness belief and views about their medicine

Statistically significant association was found between NS and 'identity' (r=.40) and 'Consequences' (r=0.29), whilst strong correlations were also found with 'Emotions' (r=0.27) and 'Illness concerns' (r=0.26). Statistically significant association was also found with CS and 'identity' (r=0.28), 'Illness comprehension' (r=0.35), 'Emotions' (r=0.33), 'Treatment control' (r=0.31) and 'Consequences'(r=0.29). NCDiff had a statistically significant association with 'Illness comprehension'(r=-0.21) and 'Treatment control' (r=-0.20) (Table 2).

Correlations between NS, CS and NCDiff and MELD and AUDIT-C score were non-significant.

Table 3: Associations (Pearson's r) between illness perceptions, severity of chronic liver disease, alcohol use and beliefs about medicines.

Explanatory variables:		**Necessity Score (NS)**	**Concerns Score (CS)**	**Necessity-Concerns differential (NCDiff)**
Illness beliefs components:				
Consequences (n=142)	r	0.29	0.29	0.02
	p	.001	<.001	.780
Timeline (n=136)	r	0.19	0.04	0.14
	p	.030	.674	.097
Personal control (n=142)	r	0.14	0.22	-0.05
	p	.089	.009	.551
Treatment control (n=139)	r	0.07	0.31	-0.20
	p	.424	<.001	.021
Identity (n=141)	r	0.40	0.28	0.14
	p	<.001	.001	.104
Concerns (n=140)	r	0.26	0.23	0.04
	p	.002	.007	.599
Illness comprehension (n=140)	r	0.09	0.35	-0.21
	p	.283	<.001	012
Emotions (n=140)	r	0.27	0.33	-0.03
	p	.002	<0.001	.713
Severity of chronic liver disease:				
MELD score (n=139)	r	0.13	0.09	0.05
	p	.122	.306	.569
Alcohol use:				
AUDIT-C score (n=131)	r	-0.16	0.03	-0.18
	p	.060	.692	.036

DISCUSSION

Belief about medicine

Patients in the Beliefs about Medicines Questionnaire (BMQ) survey scored a mean Necessity Score (NS) of 18.17 (Table 2) suggesting patient's appreciated the importance of their drugs to their health and well-being, whereas the mean Concerns Score (CS) was lower at 12.16 (Table 2) indicating patients are less worried about having to take their medication. The higher NS and lower CS are reflected in the Necessity/Concern Differential (NCDiff) mean score being +6 indicating patients are more strongly in agreement towards the necessity of their medication than towards concern. According to the health belief models (Health Belief Model, Becker 1974, and the Theory of Planned Behaviour, Ajzen 1985) in terms of a cost/benefit analysis, where beliefs held positively towards the benefit of taking medication, the patients' behavioural intentions and actual behavior are biased towards taking medication as prescribed and as a result, intentional causes of non-adherence should be lessened. Almost one in ten participants had negative NCDiff scores, indicating their belief in the necessity for taking medication was outweighed by their concerns. Theory suggests these participants would be particularly prone to intentional non-adherence. In the Pearson's r analysis (Table 3), illness belief (IB) components 'Treatment control', 'Illness comprehension' and 'AUDIT-C' were found to be significantly associated with NCDiff, suggesting patients' who believe the treatment will control their illness, who understand their illness and who reported low alcohol intake are likely to adhere to their medication.

Belief about Illness

Patients' responses indicate that their illness has a strong impact on their life with high scores on illness belief components 'Timeline', 'Concerns' & 'Consequences'. Patients also do not feel they are in control of their illness and have little understanding of their illness. Importantly both IB components 'Treatment control' and 'Illness comprehension' are the two key IB components that are associated with medication adherence. Lack of control has been the key element that predicts negative impact on intention and actual health behaviour change in a number of psychological theories such as TPB (Ajzen 1985) and Bandura's self-efficacy (1997) and these results would suggest a higher inclination towards intentional non-adherence.

In the multiple regression analyses, two of the illness beliefs components 'Identity' and 'Illness comprehension' are significantly association with BMQ component NS and CS respectively. This suggests patients' interpretation of the meaning of their illness is particularly associated with their medication adherence beliefs.

Alcohol intake and adherence

Almost a half of all participants reported that they continued to drink alcohol with over a half of these continue to consume hazardous amounts. General expectations that patients who continue to drink heavily (with a high AUDIT-C scores) might also hold beliefs that are consistent with non-adherence to medication regimes, as they are already non-adherent to one part of their treatment plan. The current study has shown that alcohol intake (AUDIT-C) has a weak association (r=0.18) with NCDiff (Table 3). This would support Horne et

al's (1999) position that there is no such thing as a non-adherent patient in medicine, and that anyone can be susceptible to non-adherent behavior and can be both adherent and non-adherent simultaneously to different parts of the prescribed treatment. An effective intervention to address non-adherence must therefore be tailored to the individual patient and to the specific treatments concerned.

Severity of illness and illness identity

No association between medication beliefs and MELD score. Patients' beliefs about their medicine were significantly more influenced by their experience of symptoms rather than by actual underlying severity.

Findings suggest that patients who gave a high score to the question "How much do you experience symptoms of your illness?" also felt a greater sense of necessity for their medication. For ALD, acceptance of having the disease, is complicated as many sufferers may be virtually asymptomatic until the end stages. Additionally the label of "alcoholic" brings negative connotations that can be difficult for patients to identify with. Blaxter and Cyster (1948) identify that some patients struggle to accept that they consume no more, or even less, than others who do not have ALD.

Illness Comprehension and education background

The IB component 'Illness comprehension' was significantly associated with CS, suggesting that the more the patient understands their illness, the less they feel concerned about the negative effects of their medication. Conversely, with

greater understanding, the cost side of the behavioural evaluation, which takes place in the HBM, is reduced. Theory suggests this would make adherence to medication more likely. Educational background was not found to be associated with any of the BMQ components in this survey and suggests that prior education is not a prerequisite to perceived illness comprehension.

The significant association between views held by patients with ALD about their medicine and the two IB components ‘identity’ and ‘comprehension’ would suggest that to address medication adherence in this patient group it is important to address the individual’s perception of their illness symptoms and their understanding of their health condition.

LIMITATIONS OF STUDY

As with all cross-sectional survey design, we are not able to establish the direction of the relationship between variables, only associations between the BMQ components and BIPQ components. Also, due to resource limitations, we collected a convenience sample and were not able to a follow-up this survey with a longitudinal approach.

CONCLUSION

Positive beliefs about medication held by patients with ALD were associated with greater sense of illness identity and comprehension. It would follow that future research should focus on patient assessment tools and tailored educational interventions designed to promote these two dimensions of illness representation.

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